

MYELOMA briefing

A PUBLICATION OF THE MYELOMA INSTITUTE FOR RESEARCH & THERAPY AT THE ARKANSAS CANCER RESEARCH CENTER

LONG-TERM SURVIVOR ENJOYS NEW ROLE AS VOLUNTEER

Ken Stoll has never attended a single medical-school class or received any formal training in treating any form of illness. And yet, he's got the kind of experience that goes a long way toward helping multiple myeloma patients deal with the unique challenges associated with the disease.

Stoll, 61, has more than just his warm, friendly smile and engaging manner to offer the patients who come to the Myeloma Institute for Research and Therapy (MIRT) for treatment. The North Little Rock, Ark., resident knows a lot about what patients are going through, having been diagnosed himself with myeloma almost 14 years ago. More or less retired after 30 years with the U.S. Attorney's Office, Stoll volunteers at the institute one day a week, serving up coffee and answers to questions posed by patients and caregivers visiting the seventh-floor clinic.

"I'm there to give any kind of encouragement or hope," admitted Stoll. "I'm not a doctor, so I can't give them any kind of medical advice. I'm glad to offer any kind of help I can."

It wasn't so long ago that Stoll's situation was similar to that of the patients he assists. In the summer of 1991, he felt a sharp pain in his chest as he was getting dressed to go to work. "I thought I was having a heart attack," said Stoll, who recognized that, even after the pain subsided, "something just wasn't right."

After undergoing a series of tests, Stoll was diagnosed with multiple myeloma and was referred to Bart Barlogie, M.D.,

Ph.D., director of the MIRT. "I didn't know what (myeloma) was, but I knew it wasn't good," Stoll said.

Following more diagnostic tests, Stoll was told by Barlogie that he could be treated



Ken Stoll

with standard chemotherapy or by what was at the time a relatively new process, autologous stem-cell transplantation. With the odds of having increased survival time from dual transplants, "I opted for that," he said.

The first transplant was done in December 1991. Given that he lived so close to the institute, Stoll chose to have the second transplant done on an outpatient basis, becoming the first MIRT patient to do so. (Almost 75 percent of transplants at MIRT are now done on an outpatient basis.)

The second transplant took place in

April 1992 even though Stoll went into remission soon after undergoing the first procedure. Stoll had the second procedure at the advice of Barlogie, and "I'm glad I did now," Stoll said. An adjusted workload allowed him to continue working before and after the transplant. "I stayed out of the court; I did things in the office instead," he said. "I had a lot of sick leave because I had never been sick before, so I just kept working the best I could."

Stoll, who retired from the U.S. Attorney's Office in 1999, contracts with the Arkansas Department of Human Services as a hearing officer in nursing home cases. He also serves as a volunteer in the Patient Partner Group at the Oasis Renewal Center, a local retreat and recovery facility.

"My main purpose (at Oasis and MIRT) is to show that I am a long-term survivor," Stoll said. "I'm proof that there is a light at the end of the tunnel."

FALL FUND-RAISER A HUGE SUCCESS

The Myeloma Institute extends thanks to everyone who responded with generosity to our fall fund-raising appeal. This year's response exceeded last year's in terms of dollars contributed by more than 60 percent! The overwhelming support helps ensure that we have sufficient donor funds, on which we depend for 23 percent of our operating and research costs. There is no doubt that the Myeloma Institute is very fortunate to have so many special friends.

IMMUNIZATION A SHOT AT A CURE

First introduced in the late 1700s to combat the spread of smallpox, vaccinations are usually associated with contagious diseases, such as influenza and childhood illnesses like measles and mumps. Frits van Rhee, M.D., Ph.D., director of the Myeloma Institute's Immunotherapy Program and an associate professor of medicine at UAMS, is taking vaccinations to another level in an effort to treat patients with advanced cases of multiple myeloma.

In February 2005, van Rhee initiated a new trial that incorporates vaccinating patients with a peptide derived from a cancer protein.

The commercially produced peptides, synthesized from human amino acids, will be injected into patients prior to receiving high doses of chemotherapy and autologous transplants. A total of 100 patients will receive three pre-treatment vaccinations and eight booster shots after receiving their treatments. The total

treatment regimen for each patient will last more than a year.



Frits van Rhee, M.D., Ph.D.

“The idea is to create an immune response to the myeloma,” van Rhee said. “Hopefully, the vaccinations will activate the patients’ immune systems, creating cells that kill myeloma cells.”

Immunotherapy has been used for several years to treat myeloma, added van Rhee,

but in the past, patients were vaccinated after receiving transplants. “By that time, their immune systems have been partially destroyed by the chemotherapy,” he said.

Patients taking part in the trial have to meet strict criteria, van Rhee said, but one advantage of this form of therapy is that it eliminates the need for more chemotherapy following transplantation. Participants can expect a response to the immunizations after three or four vaccinations, he added, but it will be several years before the true success of the trial can be assessed.

“Realistically, it will take three or four years before we can decide if this is more successful than another treatment,” van Rhee explained. “This is a new strategy, a new target, one that we hope will make a difference.”

HOLIDAY CELEBRATION HELD AT CLINTON LIBRARY

Holiday season festivities at the Myeloma Institute included a special event this year: a reception at the newly opened Clinton Presidential Center. With 500 in attendance and filled with good cheer, the

Dec. 12 celebration provided a wonderful opportunity for staff, patients who were in town, and community friends to enjoy a private tour of the museum and share the holiday spirit. The Myeloma Institute was especially pleased to welcome many colleagues from other clinical and administrative departments at UAMS. Musicians from the Rackensack Folklore Society enhanced the evening with joyful melodies reflective of simpler times during our nation's history.



Sonja McCobn, MIRT customer service manager (center), with Jim Guy Tucker and Betty Tucker, MIRT director of development



Rackensack Folklore Society musicians provide entertainment.

CALENDAR A “NUDE” APPROACH TO RAISING MONEY FOR PATIENT

The friends and family of Camille Fuller aren't afraid to display their affection for her. Or anything else, for that matter.

Fuller, of Birmingham, Ala., is currently undergoing treatment at the Myeloma Institute after being diagnosed with multiple myeloma in early 2004. The combined costs of treatment and travel to Little Rock took a toll on the savings of Fuller, 32, and her husband, Todd. Her friends and supporters, who designed a Web site, www.helpcamille.com, to promote her cause and raise awareness about multiple myeloma, debated about ways to help raise money to offset Fuller's expenses. One friend came up with the idea of printing a calendar that features photos of those closest to Fuller wearing virtually nothing, arguing that even if the calendar didn't raise any money for Fuller, it might help raise her spirits.

Dubbed “Bearing Our Souls for a Cure,” the 2005 calendar features photos of many of Fuller's loved ones, several of them in various states of undress. Local singer

Harry Wingfield strums his strategically placed guitar while gallery owner Veronique Vanblaere displays herself “clothed” with the artwork of one of her



Camille Fuller with her husband, Todd, and their son, Owen

exhibitors. The back cover features Fuller's husband and their infant son, Owen.

The calendar is on sale at a number of shops, galleries and restaurants in Birmingham, with all proceeds going toward helping Fuller pay her medical bills and transportation expenses.

ENDOWED CHAIR TO HONOR BARLOGIE

In May 2004, the chancellor of UAMS announced plans to establish an endowed chair in myeloma research in honor of Bart Barlogie, M.D., Ph.D., and his efforts toward curing multiple myeloma. The institute readily accepted the chancellor's challenge to raise \$2 million for the chair. We feel strongly that an endowed chair represents an official symbol of commitment to the Myeloma Institute and that it will ensure enduring excellence. Most importantly, funds earmarked for the Bart Barlogie Endowed Chair for Myeloma Research will guarantee that a scientist of the highest caliber gives direction to our research program aimed at curing myeloma.

To date, \$236,000 has been raised. We will be undertaking an energetic campaign to make this endowed chair a reality. For questions about the endowed chair, please contact Betty Tucker, MIRT director of development, at tuckerbettya@uams.edu or at (501) 296-1504, ext. 1634.

TWO JOIN STAFF OF MIRT

Gail Jones recently joined the Myeloma Institute as the new clinic director. Jones holds a master's degree in education and a bachelor's degree in psychology/biology, as well as an associate degree in nursing. She has more than 20 years of experience in health care management. Most recently, Jones was the administrator at the Hot Springs Rehabilitation Center in Arkansas.



Nidhi Jain, M.D., an assistant professor of medicine, became a member of the MIRT staff last fall. She is working as a hospitalist on the inpatient unit (7E).

MARATHONER RAISES MORE THAN \$6,000 FOR MYELOMA RESEARCH

Running 26.2 miles through the hilly terrain of San Francisco takes determination and will, not to mention months of training and preparation. But, what really drove Joaquin Arana to complete the grueling Nike Marathon course was his intense desire to raise funds for myeloma research in honor of his mother-in-law, patient Lynetta Kaake. He persevered through an inflamed iliotibial band (which

extends from the hip to the knee) and a fractured heel, never losing sight of the goal ahead. With creativity and a passion for some fun, Arana also masterminded a fund-raising party, complete with raffle prizes, held just four days before the Oct. 24 marathon. His efforts truly paid off; more than 65 individuals supported his cause and helped raise more than \$6,300.

NEWS CLIPS

- Thirty-five presentations from Myeloma Institute faculty were made at the annual meeting of the American Society of Hematology, held Dec. 4-7 in San Diego. Twenty-six were poster presentations, and nine were oral presentations.
- The total number of stem cell transplants in calendar year 2004 was 633.
- The total number of stem cell transplants in calendar year 2003 was 462.

ACRC GRANTS TO BE USED FOR REFRIGERATORS, EXERCISE EQUIPMENT

The Myeloma Institute for Research and Therapy received two grants amounting to \$5,742 from the Arkansas Cancer Research Center Auxiliary to pay for small refrigerators and an exercise machine – all for the inpatient unit. Twenty-nine

refrigerators are already in patient rooms, and the exercise equipment – a recumbent cross trainer that can be used by any patient – will be installed in March. The refrigerators are for use by patients and caregivers.

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